Winter 2025 Issue 154

Sideview

Working together to Beat Macular Disease

‘I can tell a story with my hands’

Marvel shares how she ‘sees’ the world with her hands

Inside this issue

- How can counselling help you?
- Top tips for navigating winter weather conditions
- The exciting new research you’re funding

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Sideview

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We're here for you

Visit our website today to find all the latest news, advice and support services.

macularsociety.org

Welcome to winter Sideview

Ed Holloway, CEO

As we bid farewell to 2025, I want to say a huge thank you to our wonderful macular community.

Thanks to your support, nobody needs to face the fear and isolation of macular disease alone this winter.

Inside this issue, you can learn more about the peer support available to you (page 30), how to access free counselling (page 28), and the exciting research developments shared at this year's Macular Disease Conference (page 8).

We also pay tribute to some of the members of our community who are sadly no longer with us (page 36). We are very grateful to everyone who chooses to remember the Macular Society after they have passed, and I do hope you enjoy reading the heartwarming stories shared by their families.

Here's to a peaceful winter and a happy new year.

Winter weather can be challenging to navigate if you are affected by sight loss. Discover our tips for staying safe and healthy on page 42.

Thank you from Lynda

Lynda shared in our summer appeal how a routine eye test revealed that she had age-related macular degeneration (AMD), a condition she hadn't come across before.

She admitted to feeling "terrified" and was very fearful for what her future might look like.

Lynda reached out to the Macular Society counselling service, which helped her come to terms with her AMD and feel more confident about adapting to any changes she might face.

By sharing her story, Lynda said: "You feel like you're contributing, like you're helping in some way towards a potential cure."

Lynda told us: "Until I was diagnosed, I'd never even heard of this condition. I'm 62 now and, up until I was 60, I had no idea what macular disease was. Considering how many people are affected, it doesn't get nearly enough attention.

"That's why raising this kind of money from one appeal is mind-blowing. People's generosity is just incredible. It really is wonderful.

"Whatever people can give, however big or small, it makes such a difference.

"Even just a few pounds matters, especially now with the cost of living being so high. For people to dip into their pockets and donate like that is such a wonderful thing, because it really does help so many people. For the appeal to raise such a massive amount of money is incredible."

THANK YOU!

from the Macular Society

We had so many lovely messages and generous donations from you, after you read Lynda's story.

Thanks to you, we raised over **£130,000** to fund a cure and **Beat Macular Disease**.

Welcome new members!

We are here to help you, so please keep hold of these contact details in case you need them.

Do you have questions about your membership?

Call 01264 350 551 or email info@macularsociety.org

Do you have questions about your condition, treatment or ways the Macular Society can help you?

Call 0300 3030 111 or email help@macularsociety.org

And during out-of-office hours, there's a wealth of information about macular disease, looking after your eyes and how to live well with sight loss at **macularsociety.org**

Help our community grow!

Do you know someone who may benefit from **Sideview**? Please let them know they can join us for free for the first six months. Find out more at **macularsociety.org/community**

Where are treatments for AMD up to?

Mr Luke Nicholson, consultant ophthalmologist and retina specialist at Moorfields Eye Hospital, joined this year's Macular Disease Conference to chat about current and future age-related macular degeneration (AMD) treatments.

> Wet AMD

Wet AMD progresses much faster than the dry form, and without treatment, many patients experience permanent loss of vision within three to six months.

Biological anti-VEGF injections have been shown to slow down or halt wet AMD progression and can help to maintain your functional vision when administered every four to 12 weeks. New drugs, such as Vabysmo and high dose Eylea, are focusing on extending the intervals between these treatments up to 16-20 weeks.

Currently, most AMD injections are inserted into the vitreous body, which is the clear gel between your lens and retina. Current research is evaluating injecting drugs into the suprachoroidal space, the space between the layers in the back of the eye, this could have a positive effect and last longer.

Eye drops are also being investigated, as well as a port delivery system – which is a small implant placed in the eye that slowly releases medication. It requires refills every six months or longer.

Looking forward, gene therapy trials are aiming to reprogramme cells within the eye. This could offer long-term control of AMD with just one or two treatments.

> Dry AMD

When it comes to dry AMD, or the advanced stage called geographic atrophy (GA), we may not be able to reverse the damage, but we can help reduce progression and assist patients in making the most of their remaining vision.

Until recently, there were no approved treatments for GA, but two new medications have been approved in the US that showed some progress in slowing progression. However, trials have noted an increased incidence of wet AMD following the injections and they are not currently approved in the UK.

There are four other treatments in phase three trials, the final stages before potential approval. These include less invasive options, such as oral tablets and an injection into the skin, rather than the eye.

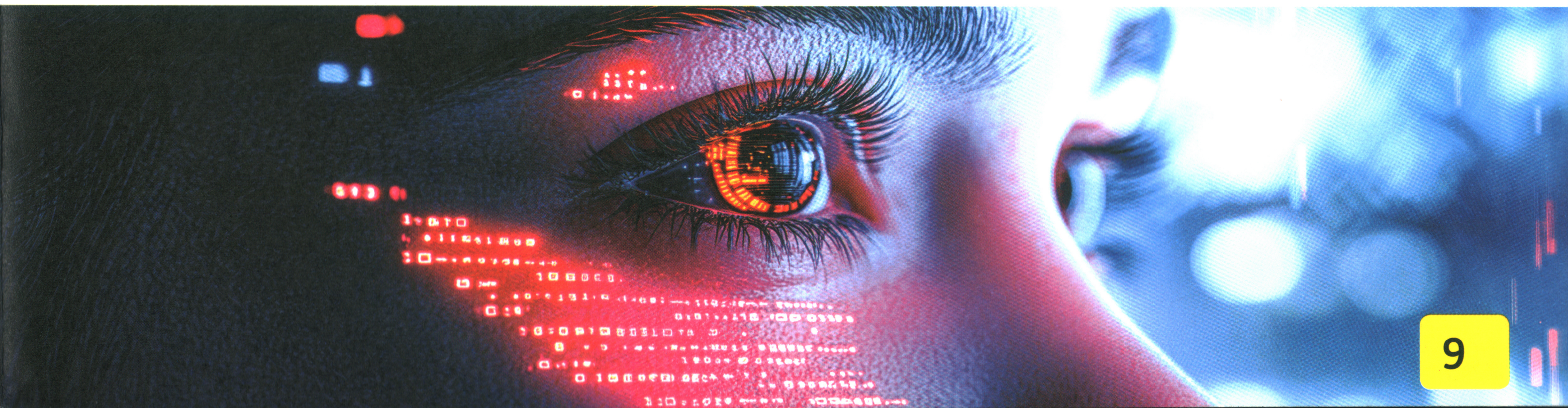
> Can my vision be restored?

Advanced technologies are exploring not only how to slow AMD but how to restore vision.

Cell replacement therapy involves transplanting healthy cells into an area of damage to rebuild the retina and restore function. It's still very experimental, but early results are promising.

Another frontier is retinal implants, tiny electronic devices that can stimulate the retina and send signals to the brain. These are being developed for patients with severe vision loss and are in their early stages.

Listen to
Mr Nicholson's full talk at
macularsociety.org/conf25



Spotlight

New research you're funding

Each year you fund exciting research grants. Here are four new projects you're funding this year.

1. Understanding the molecular mechanisms of drusen formation and therapeutic rescue in a model of macular dystrophy

Professor Jacqueline van der Spuy, University College London

Doyne honeycomb dystrophy (DHD) is an inherited condition diagnosed in early adulthood which leads to the progressive loss of vision. The condition is characterised by the accumulation of drusen (clumps of lipids and protein) underneath a layer of cells called the retinal pigment epithelium (RPE). The RPE supports the overlying light-sensing cells in the eye.

Professor Jacqueline van der Spuy and her team have previously used stem cells from DHD patients to develop an 'RPE-in-a-dish' model in the laboratory. This disease model replicates the accumulation of the drusen under the RPE. Moreover, they have developed a therapy that reduces the formation of these drusen in this patient RPE model.

A major gap in knowledge is how the genetic change that causes DHD ultimately leads to the formation of drusen. This project will use the patient-derived disease model to address this gap by assessing genetic changes and comparing these with the consequent functional changes in the cells associated with the drusen.

Comparing these changes following therapeutic treatment of the disease model will allow the researchers to pinpoint the pathways leading to the drusen formation and determine how they are rescued by the therapy.

This study will further validate the therapy they have previously developed as an effective treatment for DHD, critically highlighting which pathways are rescued and therefore implicated in the disease progression.

Turn to page 32 to learn more about Doyne honeycomb dystrophy.

Condition focus

Professor Jacqueline van der Spuy from the Institute of Ophthalmology at University College London, explains:

Doyne honeycomb dystrophy

Doyne honeycomb dystrophy is a rare, inherited macular dystrophy that causes progressive vision loss. It is passed down in fam where just one faulty copy of gene inherited from either pa can cause this disease. Doyne honeycomb dystrophy affects layer of cells in the eye called retinal pigment epithelium (R which plays a crucial role in supporting the light-sensitive photoreceptor cells.

In people with Doyne honeyco dystrophy, abnormal deposits build up beneath the RPE cells and interfere with their normal function. These deposits spread radially from the central 'macular' area of the eye, gradually expanding and merging in a typical 'honeycomb' pattern. Over time, this damage

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colour vision, light sensitivity, and a visual defect that causes linear objects to look curvy. While the onset of these visual symptoms varies, they typically begin in early to mid-adulthood. However, the deposits beneath the RPE can be present from an even younger age.

As the disease progresses, macular atrophy is the principal cause of central vision loss. Another complication of the disease is choroidal neovascularisation, which involves the abnormal growth of new blood vessels into the light-sensing retina.

Treatments

Currently, the visual symptoms experienced by Doyne honeycomb dystrophy patients are clinically managed through regular ophthalmic appointments and retinal scans to monitor the accumulation of deposits and detect any choroidal neovascularisation.

Interventions targeting this abnormal growth of new blood vessels in the retina include injections or photodynamic laser therapy. Low-energy subthreshold nanosecond laser treatments are being investigated to assess if they can stimulate beneficial changes in the RPE cells. However, photodynamic laser therapy and nanosecond laser treatments have only been trialled in a small number of patients.

Unfortunately, there is no cure for Doyne honeycomb dystrophy. However, the development of experimental therapies is underway, including strategies to remove or decrease the expression of the faulty copy of the gene in RPE cells.

Discover more about different macular conditions at **macularsociety.org/conditions**

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2. Towards a better understanding of AMD biology and new treatment strategies – Golgi fragmentation in AMD RPE

Dr Marzena Kurzawa-Akanbi and **Professor Majlinda Lako,** Newcastle University

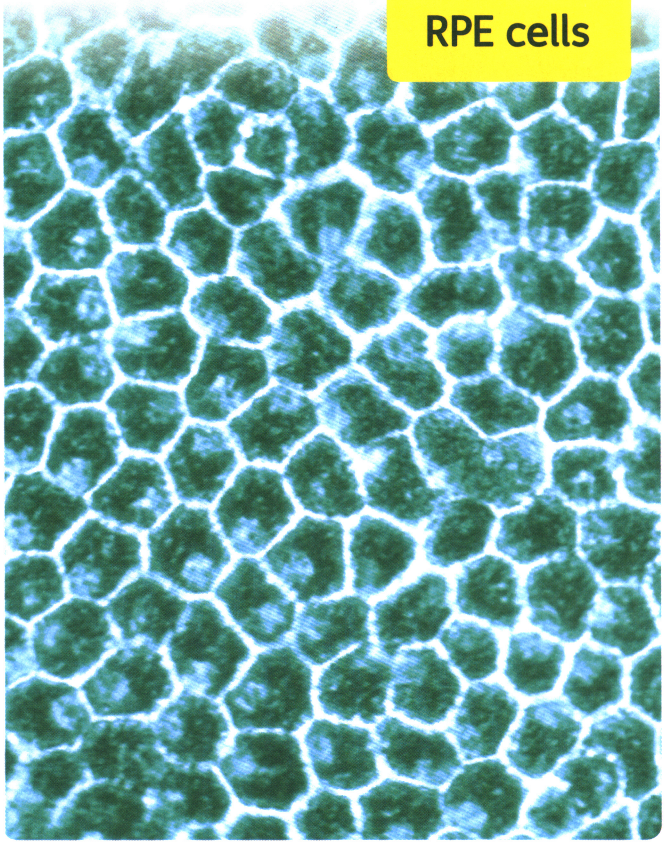
For over a decade, this team has been studying the biological basis of age-related macular degeneration (AMD). They developed a 'lab model' of retinal cells called the retinal pigment epithelium (RPE) with key features of AMD to study how these cells work. They found that the RPE recycling system is faulty in AMD. This leads to the increased production of small bubbles that spread AMD features within the retina. This shows that these cellular processes are likely important in AMD progression.

Recently, the team identified that AMD RPE have depleted amounts of the Golgi apparatus, an

continued ▸▸

organelle (a sub-unit within a cell that has a specified function) which acts as the cell's 'post office'. Here, molecules are delivered, modified, sorted, and packaged for transport to the correct destination in the cell.

The team think that malfunctions to the critical process of the Golgi may lead to the abnormalities in RPE recycling seen in AMD. This project aims to develop a deeper understanding of the Golgi anomalies in AMD RPE. Confirming these as fundamental to RPE damage in AMD will benefit the development of new therapies in this area.



3. Can a portable electroretinogram machine reduce lengthy hospital visits?

Professor Omar Mahroo, University College London, Institute of Ophthalmology

The retina detects light and generates electrical responses which allow us to see. An electroretinogram (ERG) measures these responses.

It is an important test that can diagnose patients with macular disease (particularly genetic macular diseases) and give clinicians information that cannot be obtained from other tests (such as retinal imaging). However, standard ERGs take over an hour and usually require additional visits, sometimes to distant hospitals.

Professor Mahroo's team are aiming to develop a portable ERG machine that can assess retinal health quickly and accurately, at the point of need, without lengthy visits to hospital.

4. Understanding which proteins drive the development of AMD

Dr Ben Mead,
Cardiff University

Exosomes, or extracellular vesicles (EVs), have recently been identified as a form of signalling within the body. These are small, membranous packages released from cells with a cargo of ribonucleic acid (RNA), which is received by other cells. This delivery system has a significant influence on health and disease. In dry age-related macular degeneration (AMD), exosomes released from the retinal pigment epithelium (RPE) which travel to the photoreceptors – or light-sensitive cells in the retina – have a different load to exosomes from healthy RPE cells.

Exosomes are so small (1,000 times smaller than the width of a human hair) that they can only be examined with a special nanoparticle imager. After a visual analysis, this team will look at what is in these tiny vesicles, comparing the effects of a healthy load to a toxic cargo when exposed to photoreceptors. They will then try to work out which proteins drive the development of AMD.

Thanks to teams of researchers in the UK and worldwide who are dedicated to Beating Macular Disease, research is moving rapidly.

To read more about where research into macular disease is now, visit **macularsociety.org/new-research**

Spotlight

Research news in brief

Anti-VEGF survey results

In a recent survey to better understand perceptions of anti-VEGF treatment, we asked for responses from those currently receiving anti-VEGF treatment, or who had received treatment in the last five years. Over the last few years, we have been lucky to see new anti-VEGF drugs approved in the UK and we wanted to see if patients were being offered to switch to these new drugs, and if they were able to discuss treatments and their care with their ophthalmologists.

Around half of the participants had been on more than one drug, and the most common reason for switching was to have longer intervals between injections.

Only 37% saw an ophthalmologist at every appointment and 50% said their ophthalmologist engaged with them in making decisions about treatment. When stopping treatment, 64% were happy with the discussion about why the treatment was stopped.

This survey highlights the need for shared decision-making and discussions with patients about their care and changes to treatment, especially when stopping or pausing treatment.

Thank you to all who shared their experience and views for this survey. A full report will be made available on our website next year.

For the latest research updates, visit **macularsociety.org/new-research**

Tinlarebant trial closes

In 2023 we shared news of a new pill to treat Stargardt disease, which was shown to help slow progression of the condition in some patients during phase two clinical trials.

Tinlarebant has now completed phase three trials and clinical-stage drug development company Belite Bio are compiling data ready to be shared before the end of the year.

Dr Tom Lin, chairman and CEO of Belite Bio, said: “This is an important milestone in our mission to bring a treatment to patients living with Stargardt disease.

“With no approved therapies available today, Tinlarebant has the potential to be the first treatment for this devastating inherited macular degeneration.”

The ‘DRAGON’ trial enrolled 104 adolescents across across 11 countries and assessed the growth rate of atrophic lesions, as well as the safety and tolerability of Tinlarebant.

The company is also testing whether the daily pill could prove effective in treating geographic atrophy and the earlier stages of age-related macular degeneration.

Get involved

Patients have a very important part to play in medical research.

You can share your experiences of living with macular disease, take part in clinical research or join our Research Participant Database today at **macularsociety.org/power-research**

Spotlight

Macular Society-funded research – final report

The Manchester Eye Tissue Repository genome-transcriptome project

Dr Jamie Ellingford, University of Manchester

What is the problem?

Many people with macular dystrophies don't have a genetic diagnosis. Instead, they are diagnosed based on what changes are seen in the macula. Even after getting a genetic test, the result may be inconclusive because the changes in the genes may also be found in people without the condition.

This project aimed to better understand how genetic changes can affect or lead to macular dystrophies. Understanding the genes and the variants responsible for macular dystrophies is important for more patients to receive a correct diagnosis and for us to develop treatments for these genetic conditions.

What did the researchers do?

The researchers analysed a large repository of donated human eye tissue to assess how genes are expressed in different layers of the retina.

Gene expression

This is the process by which the instructions in our DNA are converted into a functional product, such as a protein.

The researchers characterised over 200 individuals' complete genetic codes, each made up of approximately 3.5 billion letters (DNA nucleotides) arranged in a specific sequence. They identified four to five million genetic variations (differences/changes in an individual's genetic code compared to a reference sequence) for each person.

What did the researchers discover?

The researchers identified common and rare genetic variations that were found to impact on gene expression in the human retina and have been implicated in vision disorders such as age-related macular degeneration (AMD).

Their comprehensive analysis expanded the spectrum and types of genetic variants known to have a critical role in controlling gene expression in the human retina. They were able to identify novel candidate genes that increase susceptibility to AMD and found differences in how certain genetic variants affect the activity of genes already known to cause diseases.

What's next?

Studies using the results from this project will continue to develop understanding of the expression profiles, as well as the role of genetic variation in the onset and presentation of genetic disorders impacting on vision. This research could help us better understand how genetic diseases affect the retina and lead to new treatments. It would also help patients who don't have a conclusive genetic diagnosis receive a correct diagnosis to better manage and understand their condition.

Find out more about different macular conditions at **macularsociety.org/conditions**

Macular Society-funded research – final report

Turning off faulty genes to treat macular dystrophy

Professor Jacqueline van der Spuy,
University College London

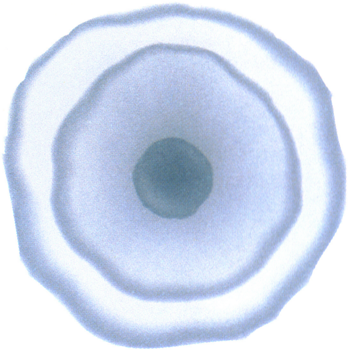
What is the problem?

Doyne honeycomb dystrophy (DHD) is a macular dystrophy which causes central vision loss in adults. Currently, there are no treatments for people with this condition. The disease is caused by a faulty gene, which holds the instructions to make a protein found in the eye. As the 'recipe' for making the protein is wrong, it doesn't work correctly. It damages and ultimately kills the cells in the macula, meaning that patients with DHD lose their central vision.

What did the researchers do?

Professor van der Spuy and her team isolated urine cells from patients with DHD and reprogrammed them to be induced pluripotent stem cells (iPSCs), which have the potential to form any cell type of the human body. They directed the iPSCs to form retinal pigment epithelium (RPE) cells in the laboratory. These RPE cells were genetically identical to the patients from which they were derived and therefore presented the features of DHD, including the accumulation of drusen-like deposits under the RPE.

The researchers then used state-of-the-art gene editing techniques to correct the genetic change

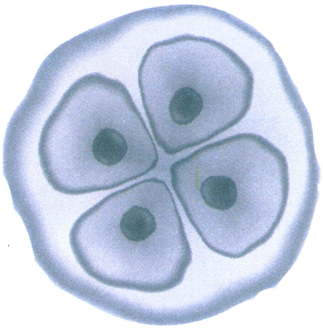


in the patient-derived iPSC, thereby engineering RPE that are genetically identical to the patient, except that they don't harbour the disease-causing mutation – what is known as an 'isogenic control' for their experiments.

They used the patient-derived RPE and their isogenic controls to explore the potential of antisense oligonucleotides (ASOs) to treat the disease. ASOs are a type of gene therapy that work to 'switch off' or suppress the expression of the faulty gene. In these studies, the patient-derived RPE cells were treated with ASOs, and the rescue of the drusen-like deposits was assessed in comparison to the untreated patient-derived RPE and the isogenic controls.

What did the researchers discover?

They found that the ASO therapy successfully targeted the faulty gene, causing a significant reduction in the levels of expression of the faulty copy of the gene compared to the normal counterpart in the patient-derived RPE. This in turn led to a significant reduction of the drusen-like deposits underneath the RPE, effectively suppressing the disease.



What's next?

ASO therapy is a very new treatment for genetic diseases. The results from this study show that ASO therapy could be used to treat DHD. This may open up the possibility of treating other dominantly inherited macular dystrophies, such as Stargardt disease and some bestrophinopathies.

Learn more about Doyne honeycomb dystrophy in our 'Condition focus' feature on page 32.

Research travel grants you're funding

This year, you have funded five travel grants to support early career researchers to travel to the **Association for Research in Vision and Ophthalmology** (ARVO) annual meeting in Utah, USA.

Ioan Matei,
Edge Hill University

Attending ARVO is an important yearly landmark for vision scientists, eager to network with peers from abroad, as well as familiarise themselves with the latest trends in all fields of vision research, from molecular to clinical.

Our group - **Ocular Molecular Biology and Mechanisms of Disease** - has two main areas of research: the retinal pigment epithelium (RPE), with a focus on mechanisms of age-related macular degeneration (AMD), and uveal melanoma, the deadliest eye cancer, aiming to identify targets for intervention. My first author poster highlighted findings of specific disturbances in physiology and metabolism occurring in RPE cells expressing a particular form of an abundant protein known to be associated with increased risk of developing AMD.

Throughout the conference, I attended poster sessions, oral presentations, lectures and symposia that are relevant to our research and the broader field. Highlights included a keynote lecture discussing the ethical and social implications of using artificial intelligence in vision science and talks on ageing, metabolism and the implications on AMD.

My participation and poster presentation would not have been possible without the generous support of the Macular Society and its members. I am immensely grateful.

Anna-Marie Muir, University of Southampton

As I am in the final year of my PhD studies, ARVO presented an incredible opportunity to network with peers, senior researchers and clinicians, and explore wider fields such as industry-related career pathways that I had not previously considered. I now feel much more prepared for thinking about what comes next in my career.

My work, titled '**Early life predisposition to diet-induced retinal pathology**' was selected for a poster presentation. It focused on evidence we found in eight and 24-week-old mice and how a high fat diet induces changes to the retina during early life, where structural changes precede functional deficits. My poster was selected by the ARVO committee as a 'Hot topic', which helped draw attention and discussion.

I received encouragement from senior scientists on further directions for my studies. This advice, combined with industry sessions and networking with funding bodies, has opened avenues into a potential fellowship or post-doctoral project in the future.

This includes a preliminary-stage application that was recently submitted to the Macular Society.

Thank you to the Macular Society for your generous support. It was inspiring to see where the field can progress to, potentially translating new discoveries into making a meaningful difference to age-related macular degeneration (AMD) patients.

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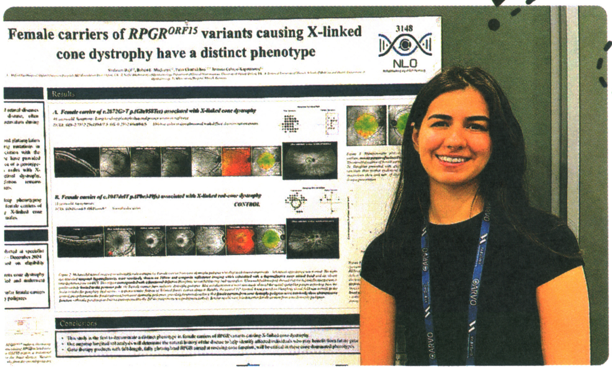

Female carriers of RPGRORF15 variants causing X-linked cone dystrophy have a distinct phenotype
3148
NLO

Shabnam Raji, University of Oxford

I had the opportunity to present my research titled '**Deep phenotyping of female carriers with distal RPGRORF15 mutations causing X-linked cone dystrophy**'.

Female carriers of X chromosome-linked diseases are often under-researched, and my research represents the first in-depth characterisation of a select group of these female carriers. The study found that functional tests, like microperimetry, were often better at detecting early signs of macular disease than retinal imaging. We also identified biomarkers that could be used to track the disease over time. This will help us understand whether the disease progresses and whether these patients might benefit from gene therapies that are currently in clinical trials for male patients.

Presenting to such a knowledgeable and engaged audience sparked insightful questions and valuable feedback that I am already incorporating into the next phase of my work and final paper, which will be submitted for publication soon.

One of the main highlights of the conference was networking with other early-career researchers and establishing connections. This is particularly important when studying rare diseases.

Thank you to the Macular Society and members for your support and for the work you do to empower researchers and improve outcomes for people living with macular disease.

As a young researcher, these opportunities are invaluable for professional development and for building the confidence and connections needed to make meaningful contributions to the field.

Macular Society news

Help **Beat Macular Disease** with a Fun Night In

Fun night in

As the nights draw in, you could fund sight-saving research and vital support services from your own home, while enjoying a fun evening among friends or family – all by hosting a Fun Night In!

Whether you enjoy karaoke, films, quizzes, board games or crafts, your Fun Night In could raise funds to help beat the fear and isolation of living with macular disease.

We can help you plan your night, provide printable posters and bunting, and give you some ideas about how to raise money from your night of fun and friendship.

Get in touch by emailing community@macularsociety.org

The results are in!

In September we launched the first monthly poll on the Macular Society website, in your members' area.

We asked you whether you had chatted to friends and family about your sight loss.

You revealed that **92%** of you had chatted to at least one person about your macular disease, with **39%** of you chatting openly to everyone.

For advice on how to chat to people about your sight loss, turn to page 28 or go to **macularsociety.org/talking**

You can log into your members' area now, at **macularsociety.org/members**

Macular Disease Conference 2025

Hope for the Future

On 13 September, more than 4,000 of you from around the globe joined our Macular Disease Conference 2025: Hope for the Future.

Thank you to everyone who joined us and for those of you who have been watching the talks back on our website.

We were thrilled to showcase an exciting line-up of macular disease experts, who shared their research projects, tips and advice for those living with macular disease and their friends and family.

The conference also included news about the latest developments in macular disease treatment and important chats with our community, where we shared personal experiences and the support available to you.

How to catch up

If you missed the Macular Disease Conference 2025 and want to catch up on the sessions, or you'd like to watch your favourite talks again at your own pace, they are all available online.

Go to **macularsociety.org/conf25**

All sessions are free to watch, and there's no need to register or download any additional software. We hope you enjoy the talks and find lots of useful information and support.

Thank you for your kind words from the day. We're really pleased to hear you found it so helpful.

"Excellent conference. Something for everyone. I like the style whereby we can pick and choose which presentations are of interest to us."

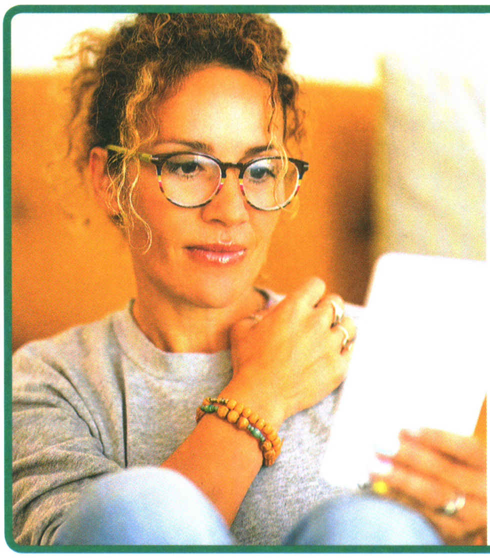
"I found it informative and useful. What wonderful work you all do."

"It was great to see the timetable, in both rooms, so I could dip in and out as I wanted."

"I enjoyed the session about Stargardt disease. I live with this condition and I'm always keen to learn of new research."

"I enjoyed Luke Nicholson's talk. His expertise just shone out of him. Listening to him speak made me feel really secure. He was very informative and truthful, which I liked very much. Thank you."

"I enjoyed people talking about their sight loss and how they try to deal with it – inspirational!"



Save the date

Macular Disease Conference 2026
12 September 2026

The conference will be free and online, so you can join from the comfort of your own home. All you need is a computer, smart TV, tablet or phone!

Here for you

Access to free counselling, from experienced and understanding counsellors, is a vital part of our Macular Society support services, and something we are very proud to be able to offer you.

Our counselling service was set up in 2000 by **Dennis Lewis**, who ran the department until 2018. Dennis had a profound impact on our macular community, and we are eternally grateful to him for all he did to support people and spread the word that there is hope after diagnosis.

Dennis sadly passed away earlier this year, but he will be forever remembered by the Macular Society and everyone he came into contact with.

Former Macular Society trustee and vice-chair Paul Ryb shared this tribute to Dennis and his lasting legacy.

Thank you Dennis

Dennis didn't just help people cope with sight loss; he helped them reclaim their lives. He understood, long before most, that the emotional and psychological toll of vision loss could be just as profound as the physical challenges.

There are those who called Dennis during their darkest days, unsure of how to move forward. There are those who found hope in his words, courage in his calm, and clarity in his unwavering belief that life with sight loss can still be full of purpose, joy and contribution.

When I received my own diagnosis back in 2007, I was disoriented, overwhelmed and afraid. I remember the moment I first encountered Dennis. He had such a remarkable energy and positive spirit. Through his words, his warmth and his wisdom, he set me on a new course. Not one of defeat or limitation, but one of service, advocacy and empowerment.

Dennis showed me that we are not defined by what we've lost, but by how we choose to move forward. Because of him, I chose to engage with the visually impaired community, not just as a recipient of support, but as someone who could offer support.

What made Dennis extraordinary wasn't just his professional acumen. He had an innate kindness that put people at ease. He was endlessly patient, deeply humble and passionately committed. He also understood the power of community. Under his leadership, the Macular Society's counselling, and peer support networks, blossomed.

Dennis dedicated his life to making sure no one had to go through vision loss alone. He believed in people. He believed in what they could become, even when they doubted it themselves. And perhaps most importantly, he believed that losing your sight doesn't mean losing your way.

Thank you, Dennis.

Macular Society
Awards for Excellence 2019
Congratulations to
Dennis Lewis
Churchill

Jackie and Dennis Lewis with Paul Ryb

continued ▸▸

Meet your Macular Society counselling service manager, Carly Johnson

› Hi, Carly. Can you tell us about your role?

C: I oversee and manage the counselling service. I go through our referrals and allocate them to our team of counsellors, and I develop our counselling and support groups so we're offering the best service we can to people who need us.

As a counsellor myself, I'm very much an advocate for counselling and talking therapies and I'm proud to offer people an opportunity to express how they feel and find coping strategies.

› How can we help?

C: We offer six free, confidential telephone counselling sessions, which can be extended to 12 if needed. These are delivered by qualified counsellors, all of whom have an understanding of sight loss. Some counsellors have macular disease themselves, and others have worked in the sight loss sector, so they bring a wealth of knowledge and understanding.

Whether you're newly diagnosed, noticing changes in your vision, or have had macular disease for a long time but are finding things challenging, we are here to help. Adapting to sight loss can feel very lonely, so we offer an opportunity for people to talk in a non-judgemental environment, without the fear of upsetting someone or getting unsolicited advice.

› Do you have any tips for talking about your sight loss?

C: I would always encourage you, where possible, to be open with friends and family about how it's impacting on your daily life, both emotionally and practically.

It can be daunting, and we often hear that people don't want to be a burden. It's not easy but it's important to be honest and chat about what you need.

> If you're supporting someone with macular disease, can you use the counselling service?

C: Anyone impacted by macular disease can gain one-to-one counselling support, and we have a specific friends and family group. This can be a really positive form of support, as there are people who understand what you're going through.

How does it work?

- You can self-refer or refer someone with their permission at **macularsociety.org/talk** or by calling 0300 3030 111.
- You will receive an introductory call to chat about what counselling can offer, which is followed up by a short telephone assessment to understand your needs.
- You are paired with a counsellor and can schedule telephone sessions at a time to suit you. Our counsellors are very flexible and can fit around any work or caring responsibilities you may have.

"I felt I wasn't alone"

Macular Society member Nicola joined this year's Macular Disease Conference to share how counselling has supported her through her sight loss.

Nicola has myopic macular disease, a condition that affects people with severe near-sightedness. Nicola, now in her 60s, revealed that it was in her mid-30s that she was told she had dry age-related macular degeneration (AMD), and what the implications could be for her future.

"I was told I wasn't going to go blind, and at that time I could see quite well. However, there was a significant change within a really short period, and it was very frightening," Nicola shared.

Over the following 30 years, Nicola's sight became progressively worse and she struggled with "feelings of despair, anxiety and depression".

"I had my own business, and I was worried that if my clients found out about my difficulties in vision, they would stop sending me work," she added.

Seeking support

After finding it "incredibly difficult" to adapt to her changing sight, Nicola reached out to the Macular Society counselling service for support.

"You feel like you're looking through a fog, or that you just miss things you can't have. You're very nervous about meeting other people or going into a room,

particularly in a work situation where you've got to meet and greet people.

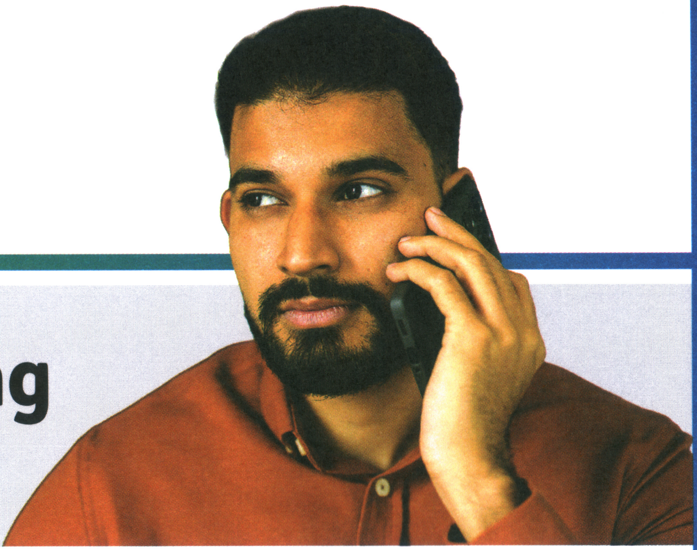
"The counselling was enormously helpful because you're talking to people who understand," she revealed.

"They understand the issues you're going through, and I felt I wasn't alone. That's a huge factor because, with all these things, you feel you're the only one sometimes," Nicola added.

Since her counselling, Nicola has a new outlook on life.

> "I think you need to be accepting of what you can and can't do. But what's most important is to concentrate on what you can do, because ruminating on what you can't gets you nowhere."

Listen to Nicola's full talk at **macularsociety.org/conf25**

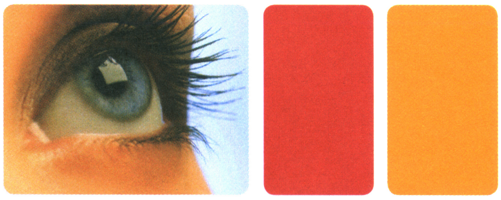


How can counselling help you?

Adjusting to a macular disease diagnosis can be scary and overwhelming. That's why we're here to help with our free counselling service. We can support you if you're experiencing:

- Anxiety, fear or worry about your future
- Low mood, depression or a sense of loss
- Grief or emotional pain around your diagnosis
- Difficulty adjusting to vision changes or hallucinations
- Isolation or loneliness
- Struggles with identity, confidence or daily life due to sight loss.

Condition focus



Professor Jacqueline van der Spuy from the Institute of Ophthalmology at University College London, explains:

Doyne honeycomb dystrophy

Doyne honeycomb dystrophy (DHD) is a rare, inherited macular dystrophy that causes progressive vision loss. It is passed down in families, where just one faulty copy of the gene inherited from either parent can cause this disease. DHD affects a layer of cells in the eye called the retinal pigment epithelium (RPE), which plays a crucial role in supporting the light-sensitive photoreceptor cells.

In people with DHD, abnormal deposits build up beneath the RPE cells and interfere with their normal function. These deposits spread radially from the central 'macular' area of the eye, gradually expanding and merging in a typical 'honeycomb' pattern. Over time, this damage to the RPE causes the overlying photoreceptors to die.

Diagnosis

DHD is diagnosed by clinical examination by an ophthalmologist. However, as it is an inherited macular condition, there may also be a family history. A definitive diagnosis is confirmed by genetic testing, which can identify the disease-associated variation in the causative gene.

Symptoms

The most common early visual symptoms include decreased ability to see fine details, reduced colour vision, light sensitivity, and a visual defect that causes linear objects to look curvy. While the onset of these visual symptoms varies, they typically begin in early to mid-adulthood. However, the deposits beneath the RPE can be present from an even younger age.

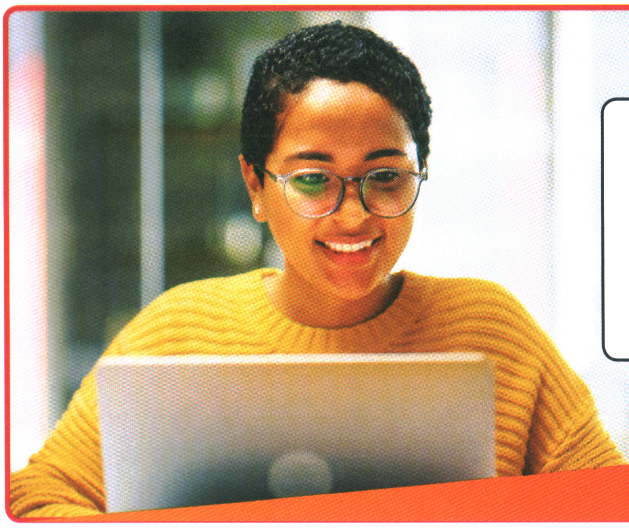
As the disease progresses, macular atrophy is the principal cause of central vision loss. Another complication of the disease is choroidal neovascularisation, which involves the abnormal growth of new blood vessels into the light-sensing retina.

Treatments

Currently, the visual symptoms experienced by DHD patients are clinically managed through regular ophthalmic appointments and retinal scans to monitor the accumulation of deposits and detect any choroidal neovascularisation.

Interventions targeting this abnormal growth of new blood vessels in the retina include injections or photodynamic laser therapy. Low-energy subthreshold nanosecond laser treatments are being investigated to assess if they can stimulate beneficial changes in the RPE cells. However, photodynamic laser therapy and nanosecond laser treatments have only been trialled in a small number of patients.

Unfortunately, there is no cure for DHD. However, the development of experimental therapies is underway, including strategies to remove or decrease the expression of the faulty copy of the gene in RPE cells.



Discover more about different macular conditions at **macularsociety.org/conditions**

Genetic counselling

Elena Schiff, genetic counsellor at Moorfields Eye Hospital, recently joined our My Macular and Me webinar to chat more about her role and the complexities of inherited macular disease.

What is a genetic counsellor?

We help people understand how their genes work and how they can influence their health. We guide them through genetic clinics and testing and chat about conditions in their family and what might be causing them.

If they choose to go ahead with testing, we explain the results and offer support. It can be quite challenging, so we are here to answer questions, like 'what are the risks of future generations inheriting this condition?'

How do genetic conditions work?

Inside our cells we have DNA, our hereditary instructions that act like a blueprint to tell the body how to make everything. DNA is arranged into two long strands, with 23 pairs of chromosomes and all the genes on them. Each gene is like a recipe for a specific protein and, so long as the DNA in that gene is spelled correctly, everything will work properly.

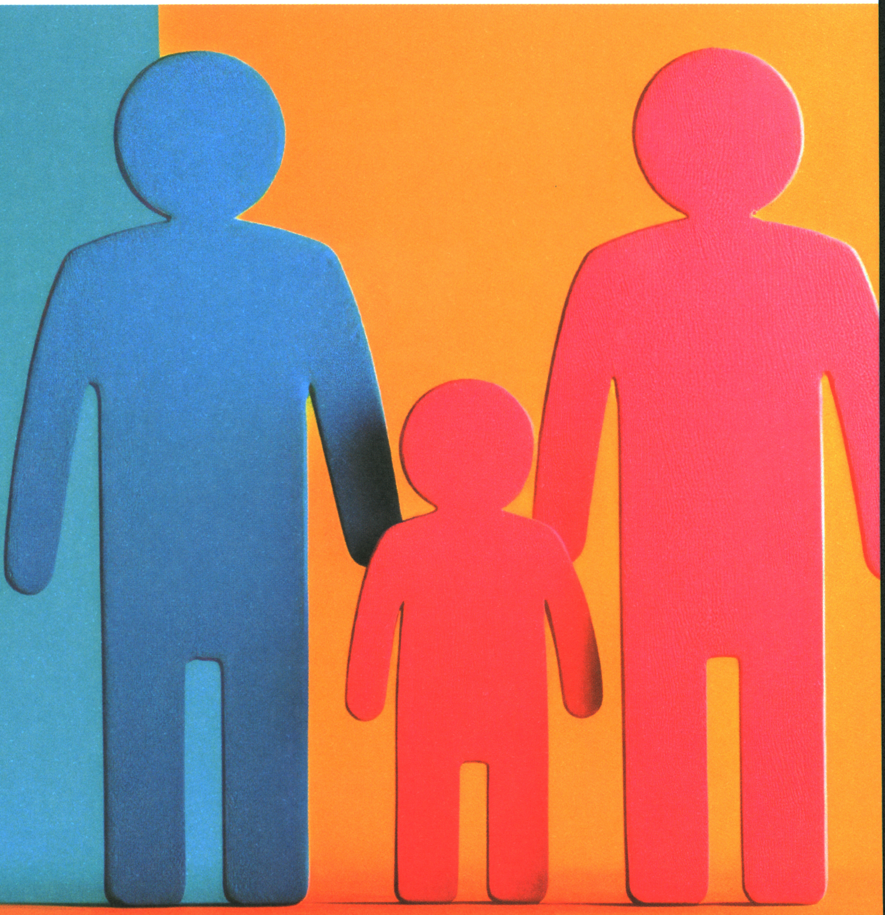
We each have one set of chromosomes, one from our mum and one from our dad. When we have children, we pass on one set, which may or may not include gene faults. Sometimes we need two healthy copies of that gene for normal function and sometimes only one.

Why do we do genetic testing?

For a lot of inherited macular conditions, there are no treatments. So why do testing?

Elena Schiff

Listen to the full webinar and more My Macular and Me webinars at **macularsociety.org/watch-now**



1. If we know what the gene is, then we know more about the prognosis.

2. Once we identify the gene, we know how it's inherited. If it's recessive, such as in Stargardt disease, it's very unlikely to be passed on. However, if it's a dominant gene, then there's a 50% chance of children inheriting it.

3. We can add your results to our database to help our research and let you know of trials that may be relevant to you months, or even years, later.

What are the difficulties associated with genetic testing?

It can take a long time to find a faulty gene, and we don't always find an answer. We may find a cause, but that could tell us more than we wanted to know, such as a gene that causes a macular condition also causing other health problems.

It can be a very emotional time, especially when discussing reproductive options, and we can refer patients for more psychological support.

Thank you for your incredible support

We are so grateful to everyone who chooses to include a gift to us in their Will, or support us by remembering a loved one. Together we will **Beat Macular Disease** and find a cure for all.

Christine MacLean

For more than a decade, Christine and Bonnie chatted every week about all things from books to gardening, and a little about their sight loss too.

Christine, who had dry age-related macular degeneration, had just turned 90 when she was partnered with befriender Bonnie.

The pair started chatting in November 2013 and hit it off straight away.

They discovered a shared passion for reading, with Christine being a former English teacher.

Bonnie shared: “Christine was amazingly independent, and very stoical. She only gave up driving because of her macular degeneration and her lack of sight. But until her mid-80s, she’d managed to socialise quite a lot.”

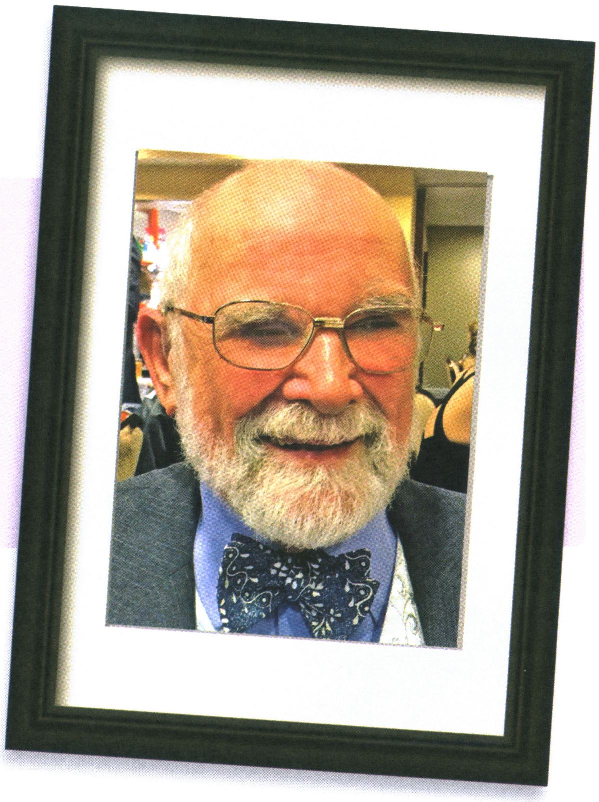
Christine, originally from Manchester, who later fell in love with Oxford during her time south, sadly passed away in April 2024. Her ashes were scattered at Somerville College in Oxford, and she generously left gifts in her Will to the Macular Society, and also to Bonnie.

In memory of her late friend, Bonnie decided to re-gift the money to the Macular Society.

Bonnie said: "I want to do something for Christine now, I want her name to be heard, and I want people to know about her."

Neale Jackson

Every year, Susan takes part in the Great North Run to remember her father, Neale. A welder, school caretaker and bassist, Neale was diagnosed with wet AMD in his 60s, before he passed away in 2023, aged 80.



Susan remembers how it impacted on his life: "It had a shrinking effect not just on his eyes, but on his world too," she said.

Susan first took on the Great North Run in 2011 and has raised thousands of pounds for the Macular Society since 2014. completing it in his memory in the last couple of years.

"We remember Dad in lots of different ways. For me, it's two and a half hours of contemplation and memories of my dad. And I will have a cry towards the finish line," she said.

"By funding macular research, I hope one day there might be new drugs to treat it, earlier screening, or perhaps it can help lead to genetic-type discoveries which can halt people from losing their sight."

continued ▸▸

Joan Duncan

August 2025 marked the first anniversary of Joan's passing when her granddaughter Helen made a donation to the Macular Society.

Helen said: "The Macular Society had been such a part of Nanna's later life, and I thought a donation would be a really good symbol for showing how much we care for her still – a loving nod to her and how important the charity has been."

Macular Society member Joan was diagnosed with dry AMD in her 80s, before she passed away aged 92. Fluent in German, she would write to her German pen pal but later relied on family to read letters she received. She also had to give up driving.

"It's sad to see someone you love go through that," said Helen.

The family discovered the Macular Society when Joan opened up about experiencing Charles Bonnet syndrome – hallucinations caused by sight loss.

Her son Alex said: "She kept on seeing a very old-fashioned London double-decker with a girl waving at her through the window. Often it appeared when she was watching TV, and she found it quite unsettling.

"The charity was able to tell her that what she was experiencing wasn't untypical – that it was her brain filling in the gaps – and she found comfort in that.

"She joined the webinars religiously because she wanted to know about the latest research and updates – and she got a great deal from that. It was comforting for her knowing there were other people with AMD, and she was very excited about the possibility of treatments emerging."

Together we will Beat Macular Disease

We are incredibly grateful for any help you would like to offer our macular community, both now and in the future.

Leaving a gift in your Will

The Macular Society has invested over £11 million in more than 120 research projects. Gifts in Wills have played a vital role in funding this. They have also helped tens of thousands of our community members access the support and advice they need.

Write or update your Will for free

The Macular Society, and our trusted partners, are here to help you write your Will for free. So, whether you want to make your Will at a local solicitor's office, online or at home, we have an offer to suit you.

You're under no obligation to include a gift to the Macular Society if you use our free Wills services. But we hope that once your loved ones have been looked after, you might consider a gift that will help Beat Macular Disease for good.

In memory

Remembering a loved one or friend by donating in their memory can be a comforting way to celebrate their life and the happiness you shared. Every donation you make helps their legacy live on.

Get in touch – If you'd like to include a gift in your Will or donate in memory, contact our friendly team on:

Gifts in Wills: wills@macularsociety.org

In memory: inmemory@macularsociety.org

Or call us on 01264 322 410.

"I'm determined to be a positive role model for my boys"

Mum-of-three Kelly recently joined our My Macular and Me podcast to chat about her experience of parenting with macular disease.

Kelly was diagnosed with Best disease, a rare inherited form of macular disease, at the age of eight. However, it wasn't until she was 35 and had had her third son when Kelly noticed changes to her sight.

She struggled with the emotional impact of her sight loss and the guilt of learning that her children, aged 14, 13 and 10, had a 50% chance of inheriting Best disease. Two of her three boys have since been diagnosed with Best disease but haven't displayed any symptoms yet.

Seeking support

Kelly reached out to the Macular Society counselling service and had six phone sessions. She told the podcast, "It just taught me to stop treating myself so negatively."

Listen to the full podcast at
mymacularandme.buzzsprout.com

Despite worrying about her boys, she added: “I’m determined to be a positive role model.”

Whether at home or getting out and about, Kelly said that she has got better at asking for support when she needs it. “You’ve got to have the confidence to tell people you can’t see something.”

School life

After receiving her sons’ diagnoses, Kelly made sure to chat to the school so they were aware of what this could mean in the future. While they haven’t displayed any symptoms yet, staff can let Kelly know if they spot issues in class and make adjustments, such as allowing the boys to sit nearer to the board.

Kelly has registered her children with the visual impairment team for education just in case they need support in the future. She advised to “try and be a wee step ahead of your sight loss because most, not all macular diseases, are a progression and if you’ve got the changes in before you need them, then it’s going to make the transition much easier.”

Kelly’s homework tip

Use your smartphone as a magnifier when checking homework. You can take pictures and zoom in or brighten the image too.

Support groups to try

Kelly recommended looking up the Blind Parents UK and the Macular Society Working Age and Young People Facebook groups.

“What you think is a stupid question might be a really simple answer for somebody else. Don’t be afraid to ask for help. I would definitely advise seeking peer support,” she added.

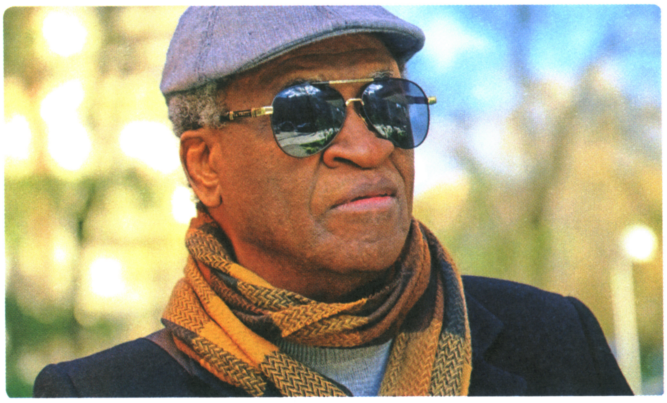
Tips for VIPs

Navigating winter weather

During the colder months, it can be more challenging to get out and about with a visual impairment. Here are some tips to make things a little easier and safer.

Dealing with glare

In winter, the sun is low during the morning and late afternoon, increasing the chance of glare. This is particularly a problem if the sun is reflecting off snow, ice and surface water.



To combat this, we recommend wearing glasses with a UV filter and choosing a hat with a wide-brim or cap.

Remain visible

Reflective armbands and brightly coloured or high-visibility coats or vests can make you more visible. This is especially important if you are walking in the dark near to roads or cycle paths.

Which cane is right for you?

A symbol cane can be helpful in reduced light as they are reflective and easy to carry in your bag.

However, you may prefer a long cane or a solid white walking stick, which help with both balance and confirming the depths of kerbs and steps.

Footwear choices

Switch to walking boots or invest in a pair of ice and snow grips – these are spikes that fit over your regular shoes to give you better grip on slippery surfaces.

Don't be afraid to ask for help

- Ask friends, family or neighbours if they can help clear your paths and steps of snow or ice.
- If you're travelling somewhere new or further from home, tell someone where you are going and when you expect to be back.

Be prepared

- Let your energy supplier know that you are visually impaired and ask to be added to their Priority Services Register. They'll then prioritise getting you reconnected if there's a power cut.
- Make sure you service your boiler regularly, especially ahead of colder weather.
- Keep your home well-stocked with food and essentials – supermarket home deliveries are especially handy.
- To avoid trips out in difficult conditions, you can arrange for your repeat prescriptions to be sent to your door. Check with your GP surgery or pharmacy to register for this service.

Stay connected

Keeping in touch with friends and family and ordering prescriptions and food deliveries can be much easier online.

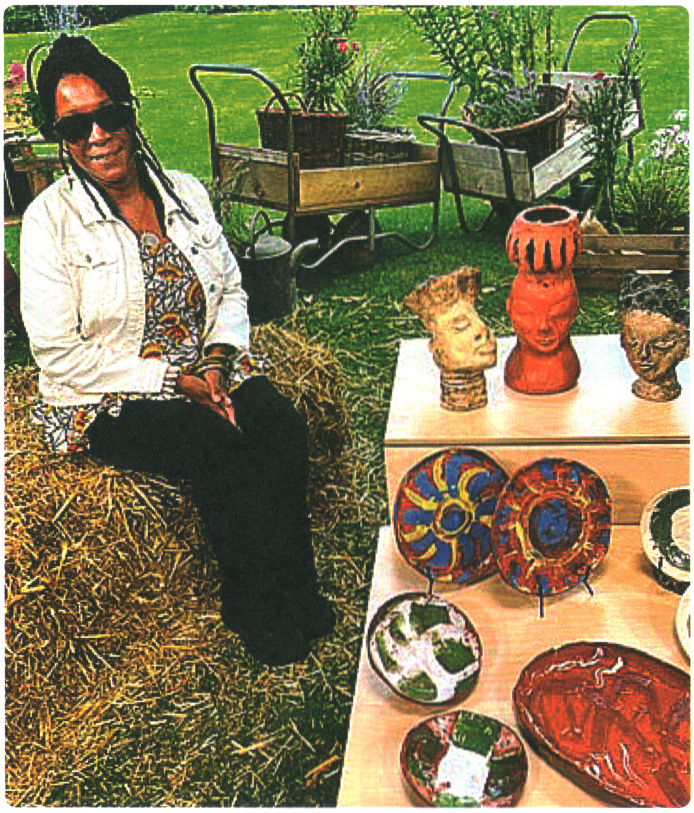
If you would like help with using a smartphone or tablet, please get in touch with our Connect by Tech service by emailing techtalk@macularsociety.org or call our helpline on 0300 3030 111.

‘I can tell a story with my hands’

While **Marvel Opara** can’t see faces, she brings them to life with her hands. We caught up with Marvel to learn more about how sight loss doesn’t hold her back from expressing herself as an artist.

Marvel first tried pottery at school and credits a wonderful teacher named Paddy for showing her how to use her first potter’s kick wheel. “I still have the vase I wrote my name across!”

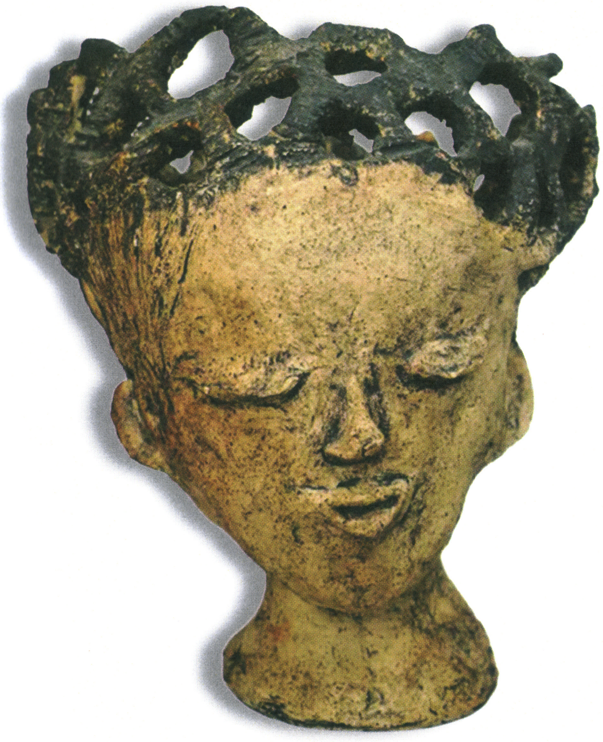
Despite no formal training, Marvel has gone on to become a very talented artist, fusing ancient Egypt, mythology, nature and her Nigerian heritage into her work.



“What I love about ceramics and sculpting is playing with the clay and exploring where it goes,” she shared.

“Clay is very powerful to work with. There are no words. You are telling a story through your hands.

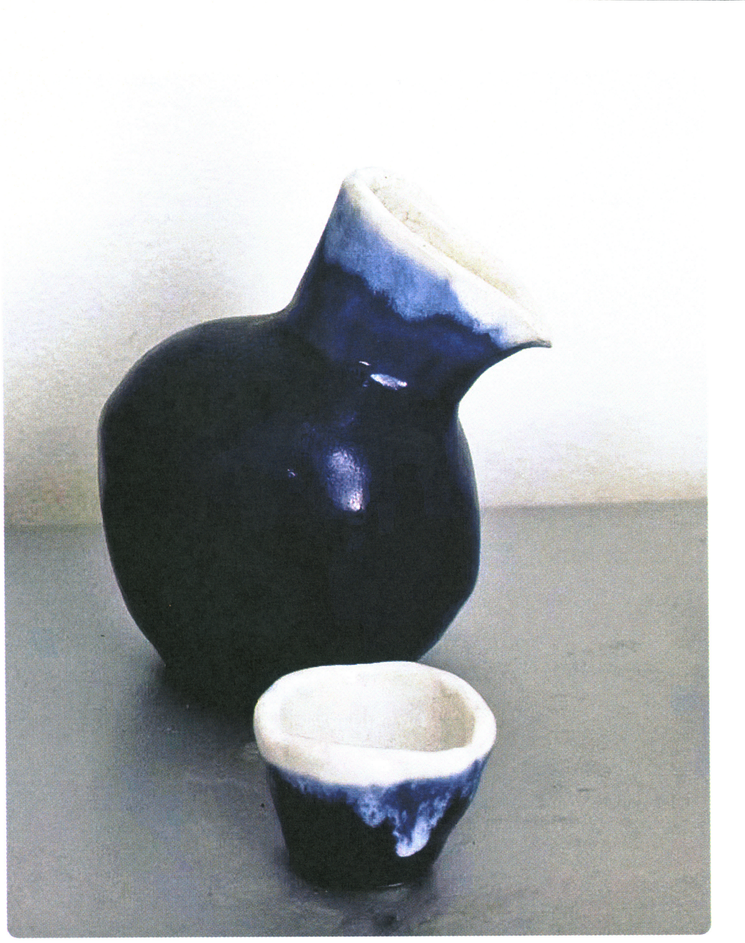
“As I am registered blind, I map the world through my dancing, moving, shaping and imagination. Clay for me is like tapping into a world within. It’s almost like I have to fill in the gaps,” she explained.



Marvel specialises in making head pots, which are sculptures of faces that can be used as bowls or vases.

“I love making head pots,” Marvel shared. “Even though I don’t see faces, I create what I perceive. This came about one day when I was trying to make a vase and it wasn’t going how I wanted it to go. I always go with the flow of the clay and how it wants to react under my hands. I turned it upside down and there I felt a face and turned it into one.”

Marvel sells her ceramic art and tableware and enjoys creating pieces on commission. She hopes one day to have her own studio with a café and exhibition space to showcase her work and the work of other visually impaired artists.



Getting started

“My advice to anyone who is visually impaired is to enrol in a class for beginners. See how you get on and discover which clay you prefer to work with.

“My favourite mediums are terracotta and porcelain, which is the most difficult to handle! You may find you prefer hand-building or working on a potter’s wheel,” Marvel added.

You can discover more about Marvel and her work at **magicmarvel8.wixsite.com/magic-marvel**

Get organised for the new year! 2026

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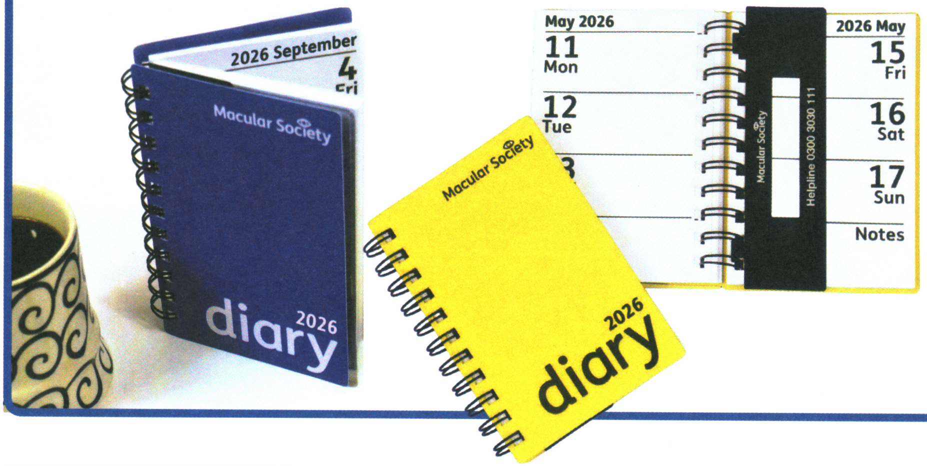
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4
Fri
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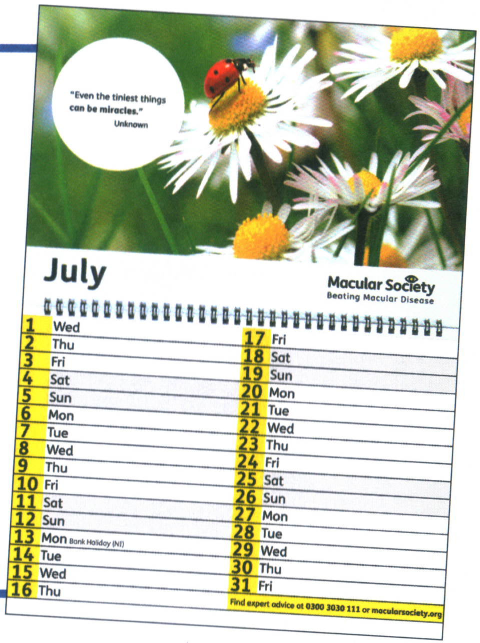
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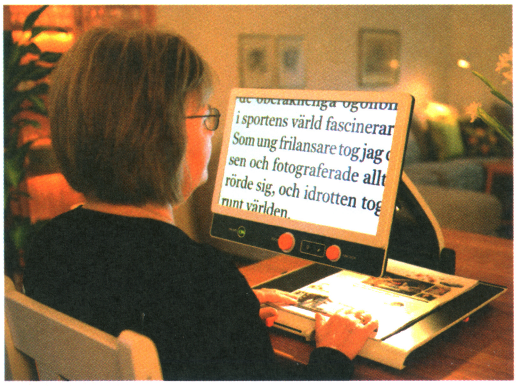

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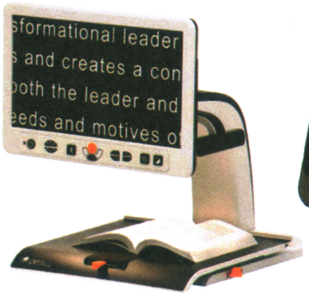

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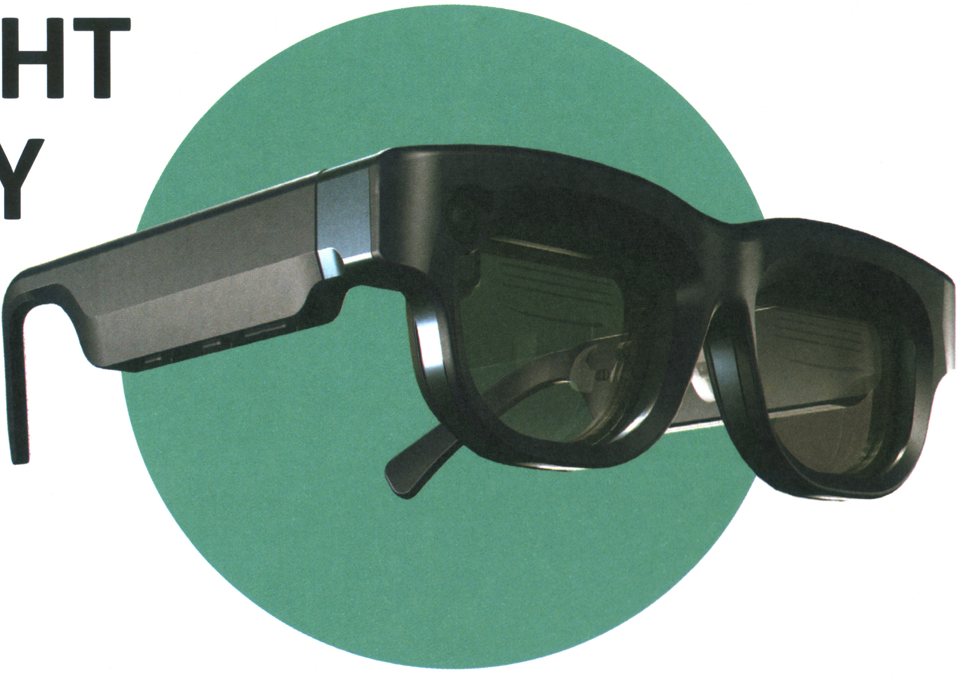

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The Smartwatch light weighs 60 grams and runs on a rechargable battery. The watch is also waterproof (ip67 - rated).

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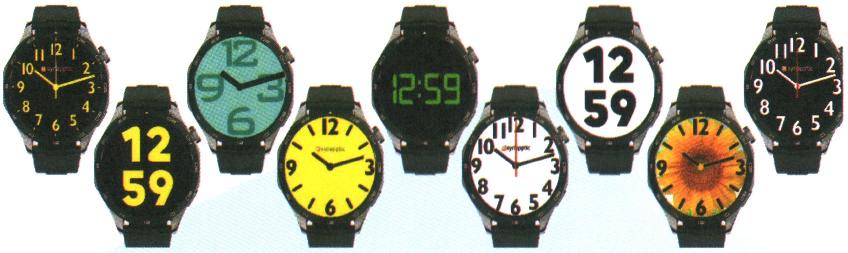
And choose a watch strap that fits your style! All smartwatches come with a black strap as standard. Additional coloured straps are available to purchase separately.

Watch Price: £150

Extra Strap £9



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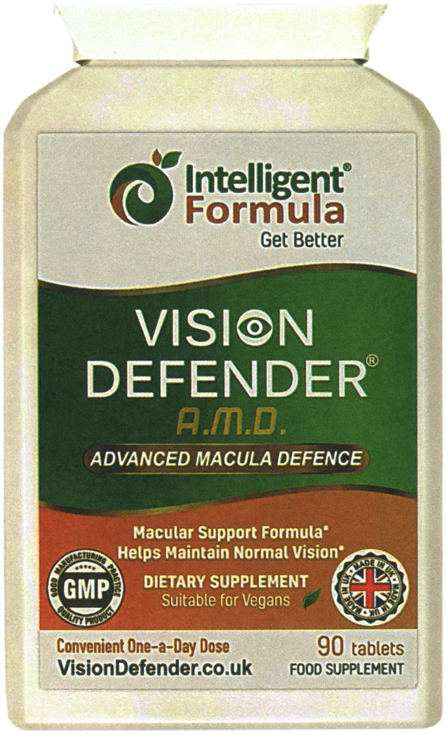
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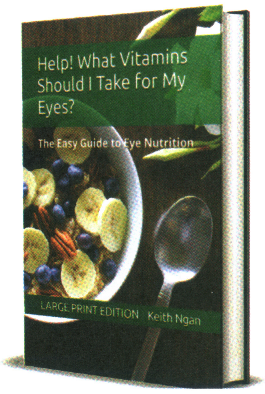
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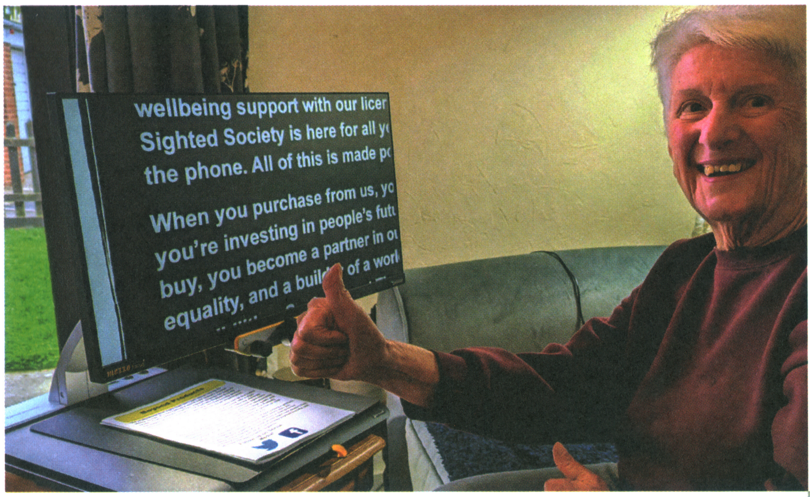

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